Abstract

The International Cancer Genome Consortium (ICGC) has been organized to launch and coordinate a large number of research projects that have the common aim of comprehensively elucidating the genomic changes present in many forms of cancers that contribute to the burden of disease in people throughout the world.

Mission

ICGC’s primary goals are as follows:

Structure & Governance

ICGC is a confederation of members that share the common goals and principles described in the policies and guidelines document and have agreed to work in a coordinated and collaborative manner within a defined structure. The members of the committees and working groups will help to provide clarity to the ICGC structure as it moves forward.
ICGC contains the following committees: ICGC Executive Committee (32 members), International Scientific Steering Committee (81 members), Ethics and Policy Committee (18 members), International Data Access Committee (9 members), Identifiability and Privacy Subgroup (8 members), Technologies Working Group (35 members), Verification/Validation Subgroup (66 members), and Data Coordination and Management Working Group (43 members).

Members consist of funding members and research members, each of which are individual or allied groups that provide a level of funding or scientific expertise sufficient to undertake at least one cancer genome project. Most projects involve the characterization of a minimum of 500 unique cases of a cancer type or subtype. More than 500 samples may be required for tumors that demonstrate considerable heterogeneity. There are circumstances when 500 samples of a tumor type or subtype may be impractical (such as a rare cancer) or unnecessary (such as a tumor subtype that is known to be relatively homogeneous, based on preexisting molecular studies). In March 2012, ICGC formalized the status of smaller projects to encourage the launch of studies of rare forms of cancer: Affiliate status will be granted to projects that are funded to study a minimum of 100 tumors. ICGC research members proposing to tackle smaller projects should provide the rationale for the choice of sample size. Each member will have the responsibility for financially or scientifically supporting a minimum of one cancer genome project. Research members must have existing or committed funds from an ICGC funding member.

It is recognized that, at the outset, potential funding members may not yet have designated funds available to support a cancer genome project and thus may be unable to immediately commit the requisite funds. Funding agencies with a prior record of funding large-scale cancer and/or genome projects will be provided an opportunity to join ICGC as observers in the absence of a qualifying research project for a period of approximately one year to allow them sufficient time to follow their normal policies and procedures to secure funds, plan initiatives of this magnitude, and make a firm funding commitment.

### Intellectual Property

The objective of ICGC policy regarding intellectual property (IP) is to maximize public benefit from data produced by the consortium. It is the view of ICGC members that this goal is achieved if the data remain publicly accessible without any restrictions.
All ICGC members agree not to make claims to possible IP derived from primary data (including somatic mutations) and to not pursue IP protections that would prevent or block access to or use of any element of ICGC data or conclusions drawn directly from those data.

Data users (including consortium members) may elect to perform further research that would add intellectual and resource capital to ICGC data and elect to exercise their IP rights on these downstream discoveries. However, if patents are pursued on such “downstream” inventions, then ICGC participants and other data users are expected to implement licensing policies that do not obstruct further research; see for example the U.S. National Institutes of Health’s document on “Best Practices for the Licensing of Genomic Inventions” (http://www.ott.nih.gov/policy/genomic_invention.html).

Data Sharing

The Data Access Compliance Office (DACO) handles requests from scientists for access to controlled data from ICGC.

Researchers and governments now recognize the great potential of data sharing for scientific research. However, caution is required when sharing data about individuals participating in genomic research because genomic data, like other types of medical data, can contain personal and identifying information. For these reasons, it is important for research projects and infrastructures to develop transparent, independent, oversight structures as well as good privacy practices. The DACO and the International Data Access Committee (IDAC) have been created to ensure that potentially identifying data from ICGC will only be used by qualified scientists for public health objectives.

The current data access officer is Yann Joly from the Centre of Genomics and Policy (McGill University). The current chair of IDAC is Martin Bobrow from Cambridge Institute of Medical Research (Cambridge University).

Sponsors & Partners

ICGC has 77 committed projects to date, in 21 tumor types and 18 countries.
On Jan. 21, 2015, the ICGC Data Coordination Center announced the ICGC data portal data release 18 (http://dcc.icgc.org), which consists of data from 12,807 cancer genomes.

Homepage

https://icgc.org/#about

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